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FINAL REPORT OF MARROW DONOR

RECRUITMENT: OFFICE OF NAVAL

RESEARCH GRANT NO:

N00014-90-J-4097

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MAY 18 1992
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NATIONAL MARROW DONOR PROGRAM
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Statement A per telecon
Capt Robert Hartzman NMRI/Bone Marrow Prog
Bethesda, MD 20814-5055

NWW 5/15/92



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FINAL REPORT OF MARROW DONOR RECRUITMENT
OFFICE OF NAVAL RESEARCH GRANT NO: N00014-90-J-4097

I. PROJECT DESCRIPTION

A. Specific Aims

The goal of the National Marrow Donor Program (NMDP) in utilizing this Navy grant was to recruit and type at least 46,000 new unrelated potential marrow donors for inclusion in the National Marrow Donor Program's Registry. Specifically, it was anticipated that by use of these funds, at least 23,000 ethnic minorities would be added to the file; the file would experience rapid growth; and increasing numbers of completely HLA-AB,DR typed donors would be added to the Registry, thus making the donor search and transplant process more rapid and economical for all patients.

It was originally planned that all funds would be used for HLA typing and none for administrative purposes.

B. Original Budgeted Categories

From the beginning, it was the intention of Congress, the Navy Medical Research and Development Command, and the National Marrow Donor Program to utilize this grant funding as rapidly as possible. Progress of the grant spending was monitored by monthly evaluations of the recruitment activity. The original plan for recruitment was:

- 1) \$1,500,000 for HLA-AB typing Minority Donors to be used to type at least 23,000 volunteer donors.
- 2) \$1,500,000 for HLA-AB typing Random Donors
 - a. \$750,000 for Donor Center Quotas to be used to type at least 11,538 volunteer donors.
 - b. \$750,000 for Family Matching Funds to be used to type at least 24,000 volunteer donors.
- 3) \$1,500,000 for Retrospective HLA-DR typing to be used to type at least 15,700 volunteer donors selected via an algorithm developed by the NMDP Histocompatibility Committee based on frequency of HLA-AB types within the NMDP Registry.

Monthly monitoring quickly demonstrated very rapid utilization of the family matching funds and a slow start for minority typing and donor center quota typing. Retrospective HLA-DR typing, however, started later in the grant period and proceeded slower than expected. Reallocation of funds to accommodate the various levels of activity was requested and obtained several times from the Department of the Navy.

In the original plan, no funds for NMDP program administration were requested. As the file grew rapidly, the financial burden to support the growth necessitated requesting that \$500,000 be reallocated from tissue typing funds to support general Program needs. This request was granted by the Department of the Navy.

C. Actual Budgeted Categories

The following report describes the actual use of the grant funds which involved three main activities related to HLA typing. These are the final budgets resulting from requests approved for reallocation of funds into other grant categories based on need and growth of the file.

- 1) \$1,474,455 for HLA-AB typing Minority Donors
- 2) \$1,870,545 for HLA-AB typing Random Donors
 - a. \$670,000 for Donor Center Quotas
 - b. \$1,150,000 for Family Matching Funds
 - c. \$50,545 for Capitol Hill Testing
- 3) \$655,000 for Retrospective HLA-DR typing
- 4) \$500,000 for administrative costs

Though there was considerable redistribution of funds from the original planned expenditures, this report will demonstrate that the original recruitment goals were not only met, but exceeded in community and minority volunteer donor recruitment. Attachment 1 provides a summary of the categories of the grant spending including the readjusted budgeted dollar amounts, actual dollar amounts, budgeted number of tests and actual number of tests performed with grant funding.

II. RECRUITMENT PROCESS AND RESULTS BY CATEGORY

A. \$1,474,455 for Minority Recruitment

1) Nineteen Centers Implemented Minority Recruitment Proposals

Before receiving the funding in Fall 1990, the NMDP surveyed all of its participating Donor Centers to determine their interest or ability to undertake minority recruitment. Nineteen centers responded outlining active programs or plans for specific recruitment within their minority communities.

The minority recruitment efforts were targeted at four main minority groups: African American, Hispanic/Latino, Asian American and Native American. The reported number of minority donors recruited by the nineteen centers at the end of July was 16,619 (See Attachment 2). Attachment 3 provides the race breakdown for the minority donors recruited by the nineteen centers during the period of this grant, with the total number of donors recruited being 19,718. The difference between the total number of donors on Attachment 2 and Attachment 3 (3099 donors) is due to the fact that many of these nineteen donor centers continued minority recruitment, utilizing funds through the event funding request process described below.

2) Event Funding Request Forms Submitted by Any Donor Center

The available minority typing funds were spent slower than expected through the original nineteen centers. In addition, opportunities emerged in areas outside the nineteen Donor Centers' service areas.

In order to have flexibility to respond to minority recruitment opportunities anywhere in the country, in March, 1991, funding was made available to any donor center that submitted an event funding request form that was approved. Attachment 1 shows that the total number of minority donors recruited with Navy grant funding was 29,073. The volunteer donors recruited through the Donor Centers' submitted requests forms is the difference between 29,073 and 16,619, or 12,454.

B. \$1,870,545 for HLA-AB typing Random Donors

1) \$670,000 for Donor Center Quotas

At the time this grant was received, many of the existing Donor Centers had accumulated lists of individuals who wanted to be typed to become unrelated volunteer marrow donors, but who were unable to participate due to lack of funding to be tissue typed, or an inability to sign up through the existing mechanisms offered by a local Donor Center, such as joining a blood program. Waiting lists at some Donor Centers included several hundred names. It was thus anticipated that recruitment from these waiting lists could rapidly take place at most centers as soon as funds became available.

Each Donor Center received a "quota" allowing them to HLA-AB type up to 150 donors from among their waiting lists or through other local "grassroots" recruitment efforts. Eighty-one donor centers accessed this funding recruiting 10,706 donors as illustrated on Attachment 1.

2) \$1,150,000 for Family Matching Funds

The Program's history has demonstrated that as new potential bone marrow transplant patients are diagnosed, many families wish to initiate volunteer donor recruitment efforts from among their friends, neighbors and within their local communities. A portion of this grant was used to match funds patients and their families raised on behalf of donor recruitment. The goal of this grant money was to relieve part of the financial burden on the patient or family who, in addition, may be confronted with many other costs associated with an unrelated donor search and transplant.

The availability of family matching funds through this grant provided the greatest impetus for the tremendous growth of the file over the last year. This program was very successful and inspired mass community recruitment in areas of the country where it had not taken place before.

Matched funds were accessed through requests filled out by local Donor Centers. Grant funds were only used to match half of the actual cost of tissue typing, phlebotomy and shipping.

The original plan was to budget funds month by month. However, the volume of requests dictated reserving funds on a first-come-first served basis with a limit of \$25,000 per patient. A total of 123 families were assisted with the average grant per family being \$10,400. Each family worked directly with one or more of 45 Donor Centers to accomplish recruitment. Attachment 4 shows the total of 44,109 donors were recruited during the eight months of recruitment using these funds.

3) \$50,545 Capitol Hill Washington, D. C. Testing

In order to provide a very visible and public arena for the Program, two donor recruitment drives were held on Capitol Hill in September, 1990. The drives served as an official kick-off to the Navy grant funding. The total number of donors recruited from the two drives was 919.

C. \$655,000 for Retrospective HLA-DR typing

1) Selection of Volunteer Donors from the Registry

The Histocompatibility Committee developed a selection process to choose donors already HLA-A,B typed for HLA-DR typing from the Registry. The strategy was developed to increase the probability that the next patient who initiates a donor search will already have a compatible HLA-AB,DR typed donor at the time of the preliminary search, or fewer donors to HLA-DR type.

In the second week of January, 1991, Donor Centers received their list of donors to contact for HLA-DR typing. Progress in this area of the grant was slower than anticipated. In some cases, Donor Center coordinators felt potential donors were less likely to respond to a request for a HLA-DR sample draw when the request was not related to a specific patient's need. A total of 2,972 HLA-DR typings were performed.

2) Six Antigen Typing on Newly Recruited Minority Donors

All Donor Centers were notified that they could arrange full six antigen typing for newly recruited minority donors. Whenever it proved logistically possible and the contract laboratory assigned for the drive could handle the additional samples, HLA-DR typing was scheduled for minority volunteer donors. A total of 4,718 HLA-DR typings were performed on minority volunteer donors at the same time as the HLA-AB testing, as noted in the actual number of tests for HLA-DR typing of minorities on Attachment 1.

D. \$500,000 for Administrative Expenses

With approval from the granting agency, funds were used for administrative expenses that developed during the course of recruitment with this grant. In terms of public education, funds were used for a public service announcement and for reprinting the main recruitment brochure.

Related to typing activities, funds were used to support the \$5.00 per donor recruitment fee billed by donor centers and recruitment groups. In addition, funds were used in conjunction with the retrospective HLA-DR typing funds to support repeat HLA-AB testing whenever donors had unsplit antigens at either the A or B locus. Table 2 shows the specific items and charges to this category of the grant.

TABLE 1
Administrative Expenses

Navy-Public Serv. Announc.	\$ 1,500
Recruitment Fees	330,315
Chance of a Lifetime Brochure	31,200
AB Split	142,713
TOTAL	\$ 505,728

III. REGISTRY ACTIVITY AND STATUS

The increase in donor recruitment activity contributed to an increase in overall Registry activity. Table 2 below provides a comparison from the beginning of the grant period to the end of the grant period.

TABLE 2
Search and Transplant Activity

	<u>September 1990</u>	<u>September 1991</u>	<u>Difference</u>
Number of donor in file	208,198	421,759	213,561
Number of Searches in Progress:			
DR Typing	444	583	
Results Pending			
MLC Test	257	427	
Results Pending			
Donor Info	9	19	
Session Pending			
Phys. Exam and/or	39	52	
Intent Pending			
Marrow Collection	49	81	
Pending			
Search Continuing	<u>245</u>	<u>376</u>	
TOTAL	1,043	1538	
Number of Transplants Completed	452	850	398

Attachment 5 also demonstrates a month-by-month increase in Registry Activity over time. Specifically, the number of preliminary and formal searches by month are included in Attachment 5.

IV. SUMMARY

This grant provided the first federal funds available for tissue typing of the general public. The early history of this Program was marked with limited donor recruitment because of available funding, not available volunteers. Many Donor Centers were able to recruit tissue typed volunteers only through their blood programs. Donor Centers had substantial waiting lists of volunteers willing to be typed, but no available funding. Lack of funding was a monumental barrier to successful minority donor recruitment, even though the Program realized the importance of having an ethnically diverse file to better serve patients. In addition, families were faced with the often overwhelming task of raising all the funds necessary to sponsor a community donor recruitment drive.

The funding through this grant allowed NMDP to recruit donors from the general population and from specific targeted minority groups, to assist families, and to add to the number of complete HLA-AB,DR typed donors in the file. Several of the most significant accomplishments during the grant period include the following:

- The file increased in size by over 213,000 donors, with nearly 85,000 donors tested through the aid of the grant funding.
- The percentage of minority donors increased by 7.7% from 5.7% of the total file being minority donors in September 1990, to 13.4% in September, 1991.
- Though less quantifiable, many Donor Centers developed considerable expertise in minority and community recruitment.

- The awareness building took myriad forms and included significant press coverage in targeted areas and individual donor center and recruitment group related activities. The Program benefited from increased public awareness regarding the need for unrelated marrow donors.
- The recruitment activities set in motion through this \$4.5 million dollar grant will be sustained as the National Marrow Donor Program utilizes the \$6.5 million dollar grant from the Department of the Navy made available in August, 1991.

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ATTACHMENT I

\$4.5 NAVY GRANT SUMMARY

24-Dec-91
 FILENAME: FINAL

NATIONAL MARROW DONOR PROGRAM
 \$4.5 NAVY GRANT SUMMARY

CATEGORIES	DOLLAR AMOUNTS			NUMBER OF TESTS			AVERAGE COST		
	BUDGET	ACTUAL	VARIANCE	BUDGET	ACTUAL	VARIANCE	BUDGET	ACTUAL	VARIANCE
150 QUOTA	\$670,000	\$616,712	\$53,288	10,308	10,706	(398)	\$65.00	\$57.60	\$7.39
MINORITY AB TYPING	\$1,474,455	\$1,481,947	(\$7,492)	22,684	29,073	(6,389)	\$65.00	\$50.97	\$14.03
FAMILY FUNDS	\$1,150,000	\$1,149,997	\$3	35,384	44,109	(8,725)	\$32.50	\$26.07	\$6.43
CAPITOL HILL	\$50,545	\$50,545	\$0		919	(919)		\$55.00	
NEW AB TOTAL	3,345,000	3,299,201	45,799	68,376	84,807	(16,431)	\$48.92	\$38.90	(\$2.79)
DR TYPING:	\$655,000			6,894					
MINORITY		\$380,900			4,718			\$80.73	
RETROSPECTIVE									
AB Split Typing		\$32,010			644 Repeat AB Typings			\$49.70	
DR Typing		\$260,812			2,972			\$87.76	
NEW DR TOTAL	\$655,000	\$673,722	(\$18,722)	6,894	7,690	(796)	\$95.01	\$87.61	\$7.40
ADMINISTRATIVE	\$500,000	\$505,728	(\$5,728)						
TOTAL	\$4,500,000	\$4,478,651	\$21,349	75,270	92,497	(17,227)			
INTEREST		\$27,647	(\$27,647)						
GRANT TOTAL	\$4,500,000	\$4,506,298	(\$6,298)						

ATTACHMENT II

**MINORITY RECRUITMENT:
19 CENTERS NAVY GRANT**

MINORITY RECRUITMENT: 19 CENTERS
NAVY GRANT

Minority Grant Funded	1		2		3		4		5		6		7		8		9		10		CENTER ACTUAL	CENTER GOAL	TOTAL
	GOAL	ACTUAL	GOAL	ACTUAL	GOAL	ACTUAL	GOAL	ACTUAL	GOAL	ACTUAL	GOAL	ACTUAL	GOAL	ACTUAL	GOAL	ACTUAL	GOAL	ACTUAL					
Banner Centers																							
Los Angeles	200	887	1200	341	200	580	1200	391	200	428	200	261	771								3200	3679	
Sacramento	100	58	100	120	100	61	100	106	100	100	100	112	100	170	400	426	100	47			1200	1200	
San Diego	200	311	200	126	200	405	1200	202	200	100	200	29	369								2200	1542	
San Francisco	250	393	250	221	250	134	250	418	250	332	250	93	98								1500	1689	
San Jose	100	252	100	61	100	43	200	112	200	131	200	463	6								900	1068	
Palo Alto	100	0	200	32	200	16	200	160	200	116	200	74	48								1100	446	
Denver	200	20	200	0	200	25	200	30	200	93	200	27	282								1200	477	
Atlanta	150	0	150	35	150	0	150	16	150	50	150	41	0								900	142	
Glenview	42	0	42	55	42	158	42	54	42	2	42	75	42	202	210						504	546	
Dedham	25	1	50	85	75	111	100	62	100	35	100	11	150	29	150	2	600	0			1350	336	
Bethesda	50	2	100	0	250	194	150	317	300	186	350	619									1200	1318	
Kansas City	200	0	200	70	200	30	200	329	200	261	200	82	40								1200	812	
Albuquerque	80	0	80	8	80	27	80	10	80	10	80	73	10								480	138	
Charlotte	0	132	500	0	500	64	0	5	0	91	0	129	71								1000	492	

MINORITY RECRUITMENT: 19 CENTERS
NAVY GRANT

Minority Grant Funded	1		2		3		4		5		6		7		8		9		10		CENTER	
	OCT90	GOAL	OCT90	GOAL	DEC	GOAL	JAN91	GOAL	FEB	GOAL	MAR	GOAL	APR	GOAL	MAY	GOAL	JUNE	GOAL	JULY	GOAL	GOAL	ACTUAL
Bonus Centers	Goal	Actual	Goal	Actual	Goal	Actual	Goal	Actual	Goal	Actual	Goal	Actual	Goal	Actual	Goal	Actual	Goal	Actual	Goal	Actual	TOTAL	TOTAL
New York	200	118	200	311	200	100	200	97	200	148	200	111	411								1200	1296
Tulsa	0	0	50	14	100	27	150	43	150	73	150	209	150								750	366
Memphis	50	5	50	100	75	21	75	4	100	20	100	73	100	115	100	100	100	87	100	15	850	540
Seattle	100	20	100	0	100	49	100	46	100	0	100	15	100	3	500						1200	133
Milwaukee	135	26	135	0	135	103	135	39	135	44	135	119	68								810	399
Monthly Totals	2182	2225	3907	1599	3157	2148	4732	2441	2907	2220	2957	2616	642	2693	1360	528	800	134	100	15	22744	16619

ATTACHMENT III

NUMBER OF MINORITY DONORS

BY CENTER AND RACE

FOR NINETEEN CENTERS

USING NAVY GRANT FUNDS

**Number of Minority Donors by Center and Race
for Nineteen Centers using Navy Grant Funds**

<u>Donor Center</u>	<u>African American</u>	<u>Hispanic/Latino</u>	<u>Asian American</u>	<u>Native American</u>	<u>Other</u>
Los Angeles	715	521	2552	29	14
Sacramento	639	236	422	19	0
San Diego	91	915	638	31	107
San Francisco	1103	88	731	10	26
San Jose	49	563	654	18	4
Palo Alto	214	43	167	11	8
Denver	37	404	34	66	24
Atlanta	78	8	280	3	3
Glenview	234	435	274	7	23
Dedham	15	9	76	0	7
Bethesda	896	81	878	10	95
Kansas City	365	283	293	34	63
Albuquerque	3	144	3	4	3
Charlotte	461	22	88	18	6
New York	694	581	900	7	17
Tulsa	0	2	1	347	0
Memphis	307	4	7	15	1
Seattle	23	28	106	29	4
Milwaukee	82	76	102	0	0
TOTAL	6006	4443	8206	658	405

GRAND TOTAL 19718

September 1991 Registry Reports

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ATTACHMENT IV

FAMILY MATCHING FUNDS

NATIONAL MARROW DONOR PROGRAM
\$4.5 NAVY CONTRACT
RECAP OF ACCOUNT 135-7162
FAMILY MATCHING

	NUMBER OF TESTS	AMOUNT OF TESTS	AVERAGE COST
LAB	---AB---	---AB---	---AB---
=====	=====	=====	=====
ARC - Los Angeles-Orange Cty	1,554	\$41,105.00	\$26.45
ARC - National Headquarters	3,306	\$85,570.75	\$25.88
ARC- St. Paul Chapter	692	\$20,295.50	\$29.33
ARC-Carolinas	2,376	\$59,400.00	\$25.00
Blood Bank of Alaska Inc.	1,672	\$41,934.50	\$25.08
Colorado Marrow Donor Program	3,000	\$75,000.00	\$25.00
Heart of America BMDR	6,107	\$152,888.00	\$25.03
New Jersey HLA Reg Foundation	7,985	\$217,227.50	\$27.20
Roche Biomedical Lab	8,300	\$208,039.00	\$25.07
SE Wisconsin Blood Center	1,654	\$53,682.00	\$32.46
 OTHER LABS	 7,463	 \$194,854.17	 \$26.11
 GRANT TOTAL	 44,109	 \$1,149,996.42	 \$26.07
	=====	=====	=====

ATTACHMENT V

**NUMBER OF PRELIMINARY AND
FORMAL SEARCHES, DR TYPINGS,
AND MARROW COLLECTIONS
BY MONTH**

10 Nov 1991

National Marrow Donor Program
The Registry - University of Minnesota

Page 1

Number of Preliminary and Formal Searches, DR Typings,
And Marrow Collections By Month

Month	Prelim Searches	Formal Searches	DR Typings	Marrow Collections
Sep 87	44	1	9	0
Oct 87	59	4	17	0
Nov 87	33	13	46	0
Dec 87	27	41	119	2
Jan 88	51	52	244	0
Feb 88	45	34	451	4
Mar 88	60	47	382	3
Apr 88	63	47	209	5
May 88	64	39	419	6
Jun 88	77	58	377	8
Jul 88	78	41	470	11
Aug 88	100	61	535	4
Sep 88	93	48	459	10
Oct 88	102	50	368	8
Nov 88	128	41	244	11
Dec 88	122	93	260	11
Jan 89	145	87	425	7
Feb 89	125	68	415	10
Mar 89	146	81	1325	11
Apr 89	145	79	1272	16
May 89	149	73	790	15
Jun 89	137	79	754	18
Jul 89	119	66	473	10
Aug 89	139	83	825	14
Sep 89	163	75	532	15
Oct 89	179	88	691	20
Nov 89	157	101	841	21
Dec 89	137	81	680	20
Jan 90	225	111	938	20
Feb 90	171	118	906	24
Mar 90	247	126	1412	21
Apr 90	191	108	1085	23
May 90	222	134	1095	22
Jun 90	199	115	1208	17
Jul 90	246	108	1273	17
Aug 90	199	131	1426	31
Sep 90	177	115	1687	29
Oct 90	247	142	1855	26
Nov 90	212	136	1905	28
Dec 90	157	136	1718	32
Jan 91	243	131	2103	33
Feb 91	222	137	2337	30
Mar 91	205	147	2776	39
Apr 91	239	186	2741	30
May 91	267	145	2128	43
Jun 91	241	130	2321	38
Jul 91	273	167	2612	29
Aug 91	316	166	2633	42
Sep 91	237	137	2834	36
Oct 91	296	148	2612	49
Nov 91	95	38	612	10
TOTAL	8014	4643	55849	929